Emotional support interventions for people with multiple sclerosis around the point of diagnosis

Section 1 – Project Details:

Maximum 800 words, using the following headings

Rationale:
Multiple sclerosis (MS) is a chronic, incurable condition, affecting over 100,000 people in the UK, with around 5,000 people being diagnosed annually\(^1\). MS is the leading cause of disability amongst young adults. The period surrounding MS diagnosis can be particularly stressful and psychologically demanding for both people with MS and their families\(^1-3\). This is a long and complicated process due to the unpredictable and extremely variable nature of MS, and the lack of single diagnostic measure. As such, patients often experience confusion, frustration and feelings of anxiety, grief, anger and fear around the point of diagnosis\(^1,2,4\). Challenges faced during the diagnostic phase of MS may also influence patients’ perceptions of MS and their relationships with the healthcare team thereafter\(^1,5\). Consequently, the way in which patients manage the diagnosis period may contribute to how successfully they adjust to MS later on. Therefore, providing support to patients around the point of diagnosis is extremely important.

The vast majority of resources deal with providing information regarding MS, rather than how to actually cope and get support around the diagnosis. Although, these information programmes improve patients’ MS knowledge and satisfaction with the diagnosis communication, they do not decrease the emotional burden\(^6\). There are no adequate support programmes or interventions to provide effective emotional support and advice to patients during this difficult and confusing period.

The importance of this area to the MS community has been highlighted by the MS Society recently awarding us a grant (as a result of a commissioned call for research on this topic). The project maps onto the UK Medical Research Council’s (MRC) framework for developing and evaluating complex interventions\(^7\), and forms the first two stages (i.e. intervention development and feasibility testing) of this process. Once these development and testing stages are completed the intervention needs to be evaluated for clinical and cost-effectiveness, in line with the MRC framework, in a definitive Phase III RCT. This proposed PhD study will be part of this ongoing project and will constitute the evaluation stage of the MRC framework.

Aims and methodology:

The aim of this proposed PhD project is to evaluate the clinical and cost-effectiveness of the emotional support intervention for people with MS around the point of diagnosis.

Proposed methodology:

Study 1: A realist synthesis will be undertaken to gain understanding of what psychosocial interventions are provided around the time of diagnosis, and the mechanisms by which an intervention works (or not). This method draws on the understanding of critical realism espoused by Pawson\(^8\) in research evaluating complex social interventions. Relevant qualitative and quantitative literature will be systematically reviewed and synthesised using Pawson et al.’s\(^9,10\) guidelines on the methodology for realist synthesis. This will (i) further refine the intervention and (ii) inform the (later) implementation strategy.
Study 2: A multi-centre Phase-III randomised controlled trial (RCT) will be conducted to evaluate the clinical and cost-effectiveness of the emotional support intervention for pwMS around the point of MS diagnosis. All the necessary parameters (e.g. sample size) for the optimal design of this definitive trial will be based on the findings of our currently ongoing feasibility trial (which will be completed before the commencement of the full trial). Participants will be randomised after baseline assessment to one of the three groups: usual care, usual care + face-to-face support, or usual care + online support (ratio 1:1:1). Participants will be assessed at baseline, and 3 and 6 months after randomisation. Outcome measures will assess how well participants cope with the diagnosis, their level of perceived stress, self-efficacy, emotional wellbeing, quality of life and employment. A resource use questionnaire will also be collected at three time-points from participants to evaluate the cost-effectiveness of the intervention.

Study 3: Feedback interviews: We will invite up to 30 participants from the RCT (10 from each group) to take part in a semi-structured, face-to-face/telephone interviews about their experiences of the intervention. Purposive, maximum-variation sampling will be used. Interviews will explore participants’ experiences of diagnosis, support expectations and how they felt following the intervention. Participants will also be asked about their experiences of receiving the intervention and have the opportunity to report on what they found helpful and unhelpful about the intervention, its content and delivery. Feedback interviews will be analysed using thematic analysis.

Benefits and suitability as a PhD project: We believe this to be suitable as a PhD project as it offers the PhD student the opportunity to develop expertise in three different methods: literature (realist) reviews, RCT, and qualitative research. This is a cross-divisional and interdisciplinary research project. The research team of the ongoing feasibility trial will provide support and advice to the PhD student. We also have an international network of collaborators who have agreed to provide a virtual advisory board for the PhD project. Because the topic area has the support of the MS Society, it will also form the basis for a postdoctoral grant application to the MS Society.

Key References:


Section 2 – Training Provision:

Maximum of 250 words. Please detail the training provision that will be made available to the student.

Embedding the PhD within the MS Society-funded project will provide the PhD candidate an opportunity to work collaboratively with a multidisciplinary group of researchers who have expertise in MS research, and learn through them how large-scale multi-centre RCTs are conducted. This will equip them to produce high impact outputs and place them at an advantage when applying for a postdoctoral fellowship to pursue a career as an independent researcher. In keeping with the complimentary, but different, areas of expertise offered by the two supervisors, each supervisor will offer supervision in separate areas. Dr Evangelou, a neurologist with clinicoal experience in MS, will provide links with MS clinical services and advice on implementing the emotional support intervention in practice. Prof dasNair, a clinical psychologist and neuropsychologist, has expertise in psychological interventions, and RCT, systematic review, and qualitative methods. He will train the student in these methods, guiding the research processes, and methods of analysis. The PhD student will be based at the Division of Neurosciences. They will have access to courses offered by the Graduate School of the University of Nottingham which would help them acquire a range of personal and professional skills. They will receive appropriate formal training from relevant courses from the School of Medicine, and statistical advice from the statistics drop-in clinics. Health economics support will be offered by the Swansea Centre for Health Economics. Towards the end of the PhD, they will enrol with the School’s grant writing workshop (to prepare the postdoctoral application).